

State of Autism 2016: Autism Across Kentucky

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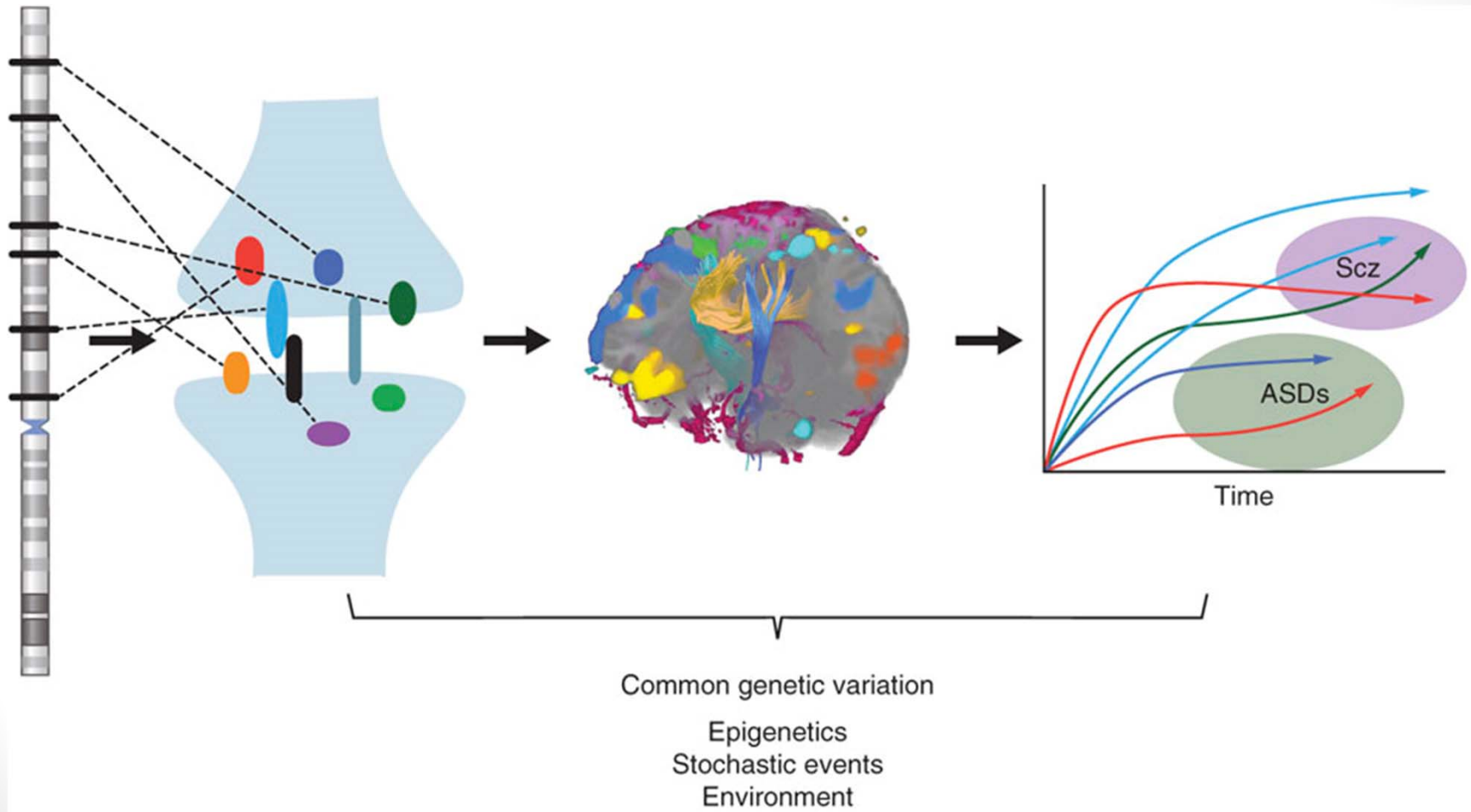
Overview

- Delineate current challenges for healthcare delivery to autism families in the State of Kentucky
- Highlight recent trends in research and personalized medicine which will impact autism care
- To define current best practice models for healthcare delivery to autism families
- To define future models of healthcare deliver in the State of Kentucky

Introduction

- Autism Spectrum Disorder is a classic pediatric neurobiological disorder defined by:
- Impairment in communication
- Impairment in social function
- Presence of restricted interests and repetitive behaviors

Big Picture



Autism as a Multi-System Disease

- Developmental peds
- Psychology
- Speech pathologist
- Occupational therapist
- Child psychiatrist
- Teachers
- Social workers
- Peds Sleep medicine
- Peds GI
- Peds Neurologist
- Peds Genetics
- Peds Endocrine
- Core symptoms
- Behaviors
- Psychiatric (bipolar, catatonia)
- Insomnia/night wakings
- GERL/constipation
- Obesity/diabetes
- Seizures
- Metabolic dz (carnitine, folate, amino acid, mito disease, etc)

Challenges

- 1:50 in children 6-17 years of age
- Prevalence: 9 per 1000
- 40,000 individuals in KY

- Lifetime costs: \$3.5-5 million dollars
- Individual therapy: \$50,000/year under age 8 yrs
- Families earn 30% less

Challenges-Examples

- No specific state agencies who serve individuals with autism
- In 2007, 7004 students with autism under 18.
- According to KY state 2007 data, 2367 students with autism received special education services.

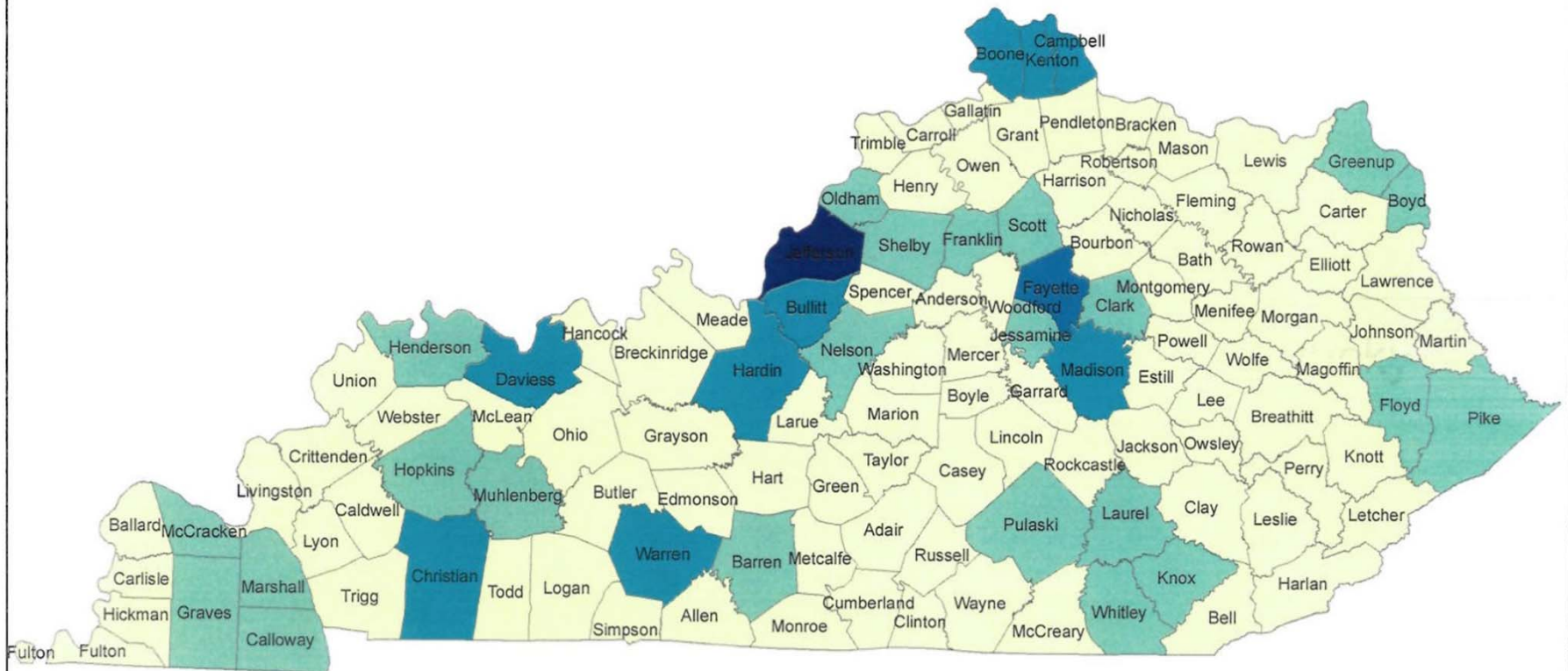
Challenges- Few Pediatric Providers

- ULAC at Kosair Charities (KATC/STAR/Bingham)
- KATS Network (Assisted Technology)
- ECU Autism and Related Disorders Group
- WKU Kelly Autism Program
- Autism Services Research Group (UK Human Development Institute)

Even Few Adult Providers

- Lee Clinic (Central Kentucky)
- Oakwood (Eastern Kentucky)

Estimated Number of Individuals with Autism in Kentucky (Lifespan)



Estimates by County

	26 - 333		334 - 745		746 - 1815		1816 - 3361		3362 - 8422
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Towards a New Approach in the State of Kentucky

Implications of International Data for Kentucky

- Better education of parents, teachers, and primary care providers to screen for ASD.
- Look at our autism work force, their centers, and their locations.
- More precise funding and specificity of the deliver of autism services.
- Better tracking of our outcomes in ASD.

Kentucky Needs Paradigm Shifts

- Early identification by rapid state of the art assessments.
- Valid scientific methods to rapidly define and treat the affected neural circuitry within an individual child.
- Active educational state wide network of universities/autism providers to provide latest information about the relationships between biology of the child, assessment, and treatments.
- This paradigm shift require 1) collaborative network of providers and 2) brain trust (core faculty/providers) who also participate in research

CAUTION

- *The gold standard and validated instruments in autism research in human biology are at best only fair measures.*
- *We have yet to create a good instrument to measure the output of individual neural circuitry which mediates a given human behavior or cognitive output.*

Evidence Based Treatment in ASD-2006

- Behavioral approaches-
- Categories
- **Pro-Social and Play-Related Interventions-** social stories, peer-mediated instruction, social script training
- **Language and Communication-based Interventions-** AAC, PECS, verbal behavioral approach
- **Intervention for Challenging Behaviors-** positive behavioral supports

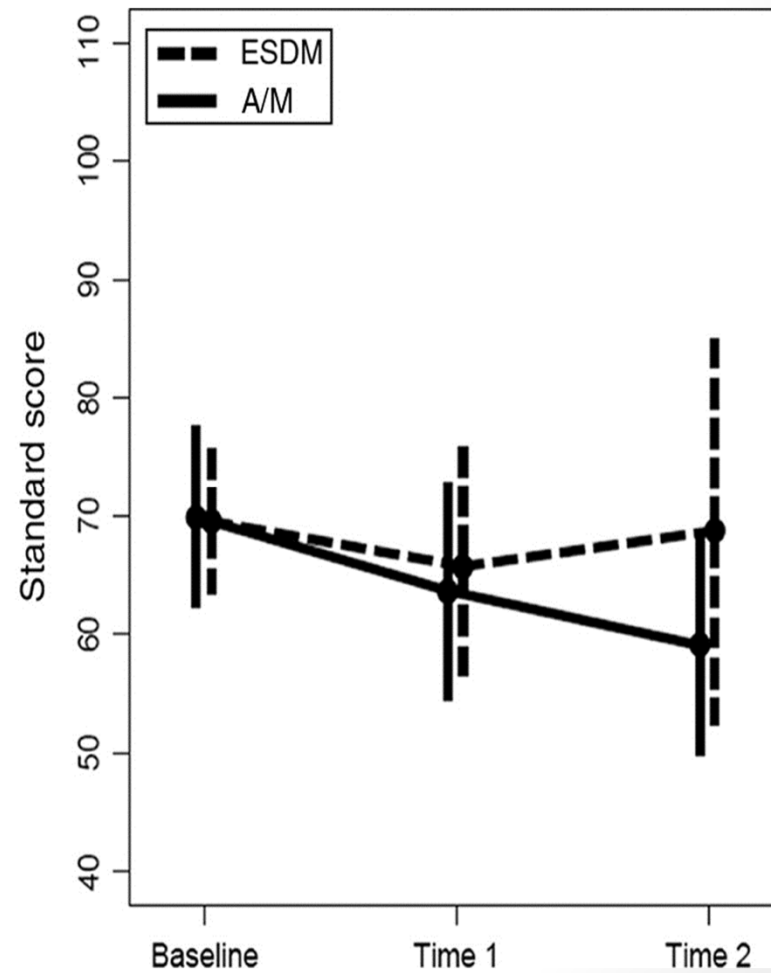
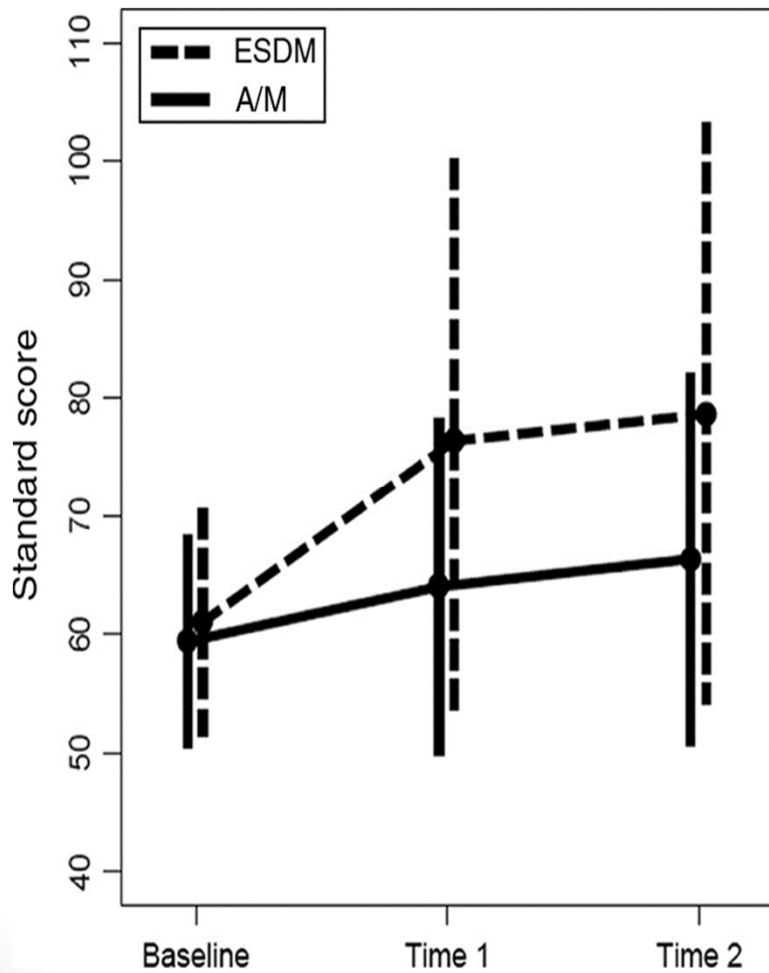
Evidence Based Treatment in ASD-2006

- **Biomedical Interventions-** none
- **General Skill Building-** behavioral teaching, environmental supports/structure, picture activity schedules
- **Expressive Psychotherapy –** CBT
- **Comprehensive Programs-** TEACH, Denver Model, DIR Model, IBI
- **Family-Based Interventions-** parent education, parent support groups, communication/relationship parent training, behavioral parent training, respite care

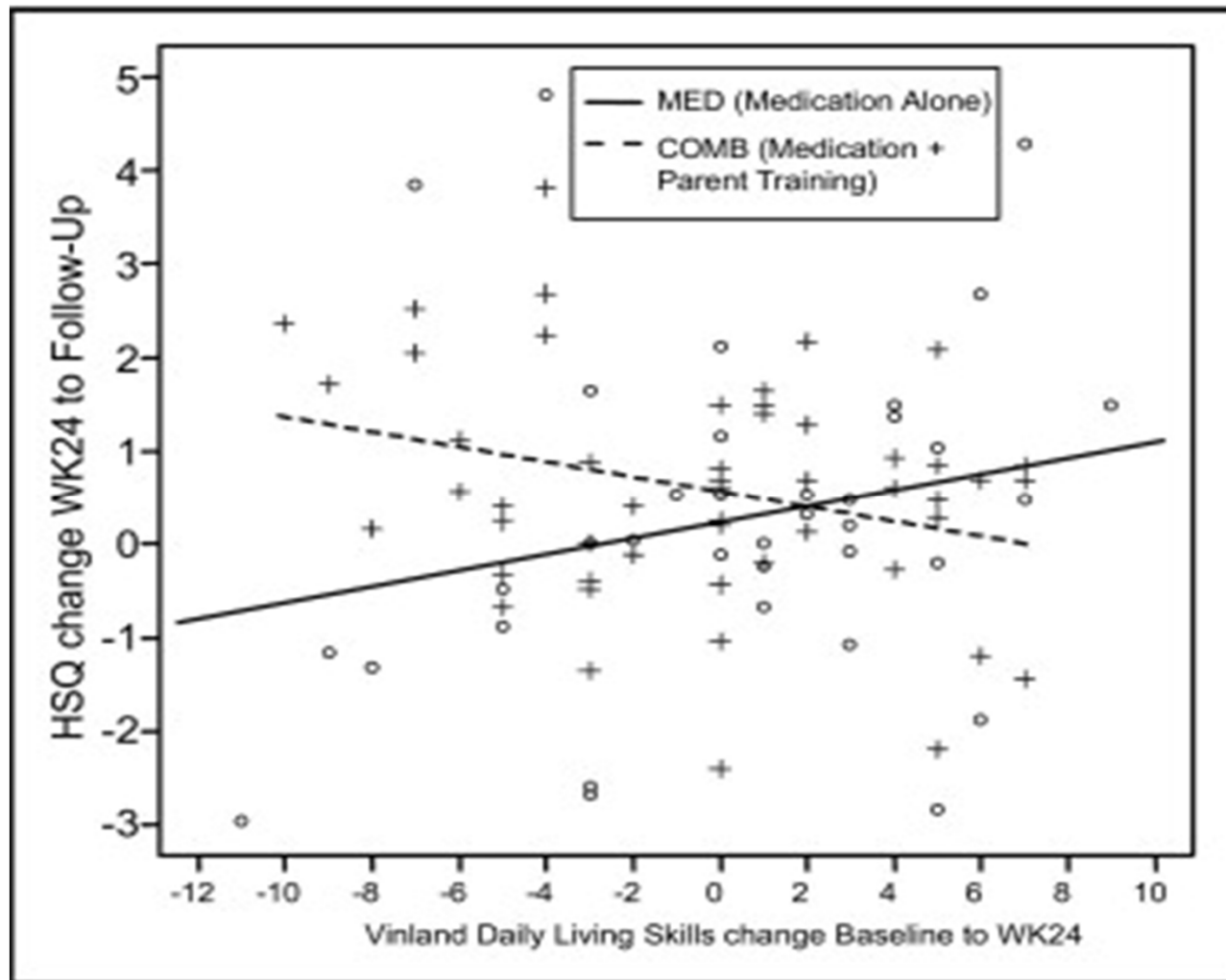
Evidence Based Treatment in ASD-2014

- **Biomedical Interventions-** Abilify*, Risperadal*, Fluoxetine, Methylphenidate*, Atomoxetine, Valproic acid
- **Comprehensive Programs-** Early Start Denver Model, EIBI
- **Combined Approaches-** Risperadal + Parent Training

Evidence Based Treatment in ASD-2014



Evidence Based Treatment in ASD-2014

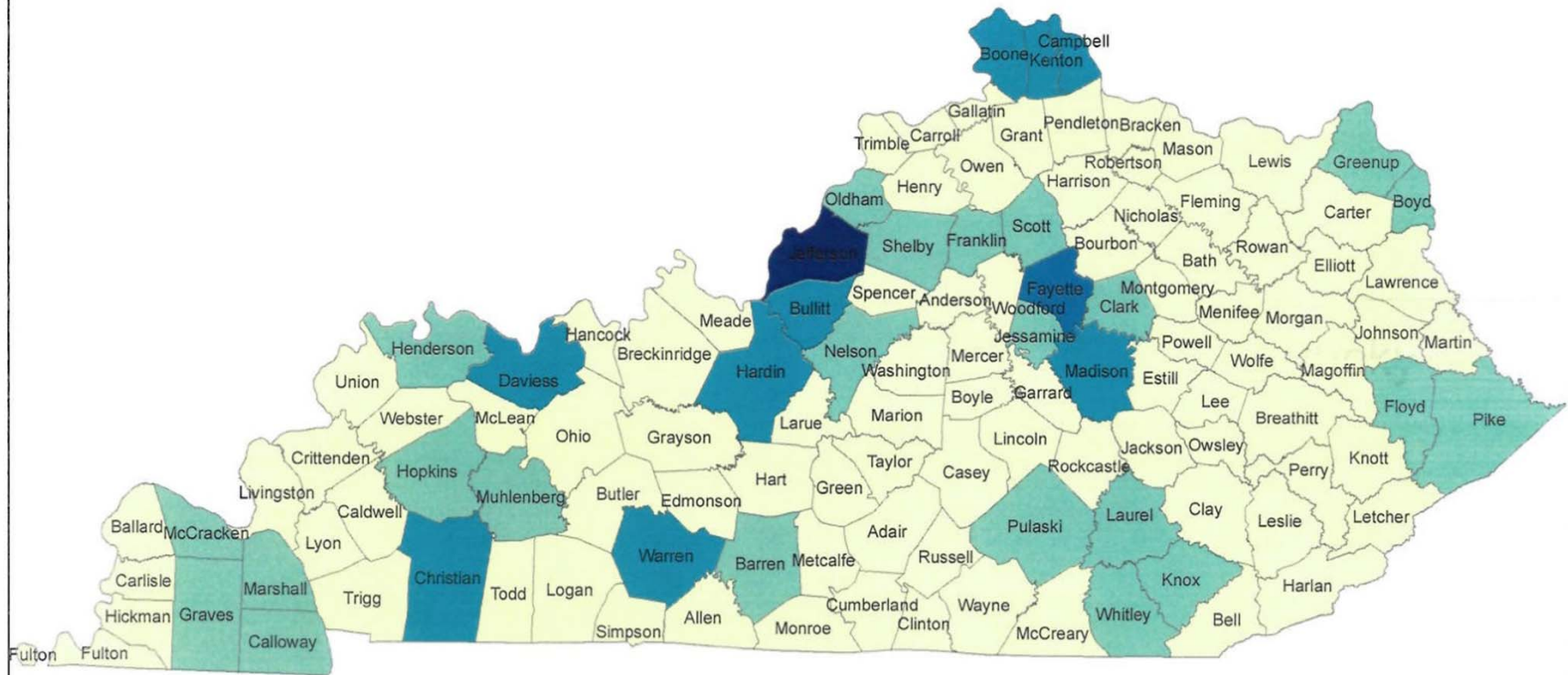


Summary of Evidence Based Practice Methods

- There is good evidence for a wide variety of behavioral approaches that positively impact cognitive skills, social/communication skills, and adaptive skills.
- There is some evidence for pharmacological interventions. Medication intervention may be enhanced for behavioral approaches.
- There is no best practice evidence that neurologic, sleep, or GI interventions that positively impact cognitive, social/communication skills, or adaptive skills.*

Back to the Needs.....

Estimated Number of Individuals with Autism in Kentucky (Lifespan)



Estimates by County 26 - 333 334 - 745 746 - 1815 1816 - 3361 3362 - 8422

Senate Bill 185: KY
Office on Autism and
KY Advisory Council on
Autism Spectrum
Disorder

History in Kentucky

- 2005 - Commission on Autism Spectrum Disorders (HB 296/KRS 194.A620-622)
- 2006- *Commission on Autism Spectrum Disorder* convened to assess the needs of the state and developed and submitted a report to the Governor with 15 recommendations including a timeline for implementation
- 2006 - Commonwealth Council on Developmental Disabilities created a subcommittee on ASD and continued to monitor and report progress
- 2007 - Commission on Autism Spectrum Disorders was dissolved upon completion of the report

History Continued

- 2011 - Department of Behavioral Health, Developmental and Intellectual Disabilities initiated a Collaborating Committee on ASD
- 2011-2013- Collaborating Committee brought together key state agencies and families to address life span issues and service gaps
- 2013- Advisory Council on ASD and Office of Autism were created
- 2014 – First Advisory Council on ASD report to Governor: *Creating a More Secure Future for Kentuckians Affected by Autism*
- 2015 – Governor appointed representatives from U of L and UK as Advisory Council Co-Chairs

Kentucky Advisory Council on ASD

Mission & Vision

Mission: The Advisory Council on Autism Spectrum Disorder promotes collaborative efforts and advocates to improve system of supports for individuals with autism spectrum disorder and their families across Kentucky.

Vision: Individuals with autism spectrum disorder of all ages are engaged in self-determined lives and are recognized as valued citizens in the community.

The Office of Autism was established to:

- Create a centralized location to coordinate statewide and regional efforts to enhance the quality of life and independence to individuals with ASD and to support their families and caregivers
- Improve coordination of autism resources within the system of care supporting children and adults with autism and help make those resources available to families and self-advocates
- Be the center of a communication network sharing autism-related information among state agencies
- Provide administrative support to the Advisory Council on ASD to unify and promote initiatives aimed at improving Kentucky's system of supports to autism families

- April 1, 2016 Signing of SB 185 into law KRS 194A



Current Membership- KY ACA

- Co-Chairs: UK and U of L
- Family Members
- Self -Advocate
- Participating Agencies
 - Department for Community Based Services
 - Department of Public Health
 - Department for Medicaid
 - Department of Education
 - Office of Vocational Rehabilitation
 - Department for Behavioral Health Developmental and Intellectual Disabilities

Current Membership - Cont.

- First Steps
- Commonwealth Council for Development Disabilities
- Education and Professional Standards Board
- KY Division of Protection & Advocacy
- ARC of KY
- UK: Human Development Institute & UK CASPER Center
- U of L: Weisskopf Child Evaluation Center, UL Autism Center, & KY Autism Training Center
- Department of Juvenile Justice
- Office of Autism

Advisory Council

- Meets Quarterly (as an effort to include statewide participation we have an interactive video conference at 7 locations statewide)
- Works Through Its Subcommittees
 - Early Childhood
 - School-Age
 - Adolescent Adult
- Subcommittee Membership is Broader Than the Council, and Includes Additional Family Members and Self-Advocates (Inclusive Participation)

Ensuring Collaboration

- Office of Autism is currently housed at both UK and U of L. Universities contribute space and office support in-kind.
- Director of Office of Autism works very closely with both Universities to create new collaborations between UK, U of L and other state universities (e.g., LEND grant proposal)
- This arrangement really ensures true state-wide outreach and community engagement.
- **Coordination of fiscal and human capital statewide**

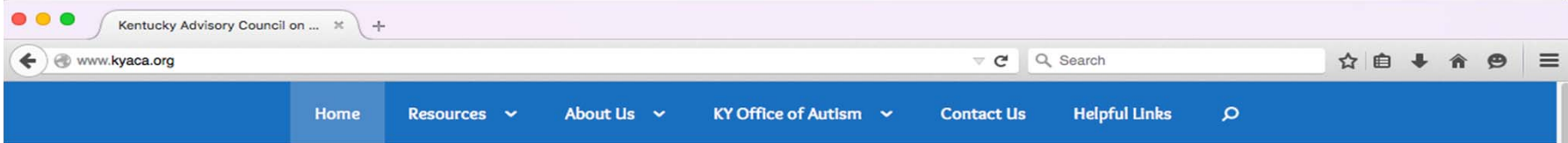
Results of Collaboration

- Coordinated information for families across medical, education, behavioral health and developmental disabilities
- UL, UK, ECU federal LEND training grant application including 21 Faculty
- Regional Parent Summits (e.g., Western KY 2015 Eastern KY Summit in April 2016)

Collaborative Efforts

- Business Service Team Training Project ISAW
- KY Advisory Council Website: www.kyaca.org

KYACA.ORG Home Page



Kentucky Advisory Council on Autism

Improving Kentucky's system of care for individuals on the autism spectrum

Find Resources by Age Group

November 6, 2015 by trex



Contact us:



Recent News

Parent Summit April 15-16, 2016

Find Resources by Age Group

School Age Subcommittee Meeting

Early Childhood Subcommittee Meeting March 22, 2016

1:00-2:30pm EST

Adolescent /Adult subcommittee meeting

News by Category

Adolescent Adult

Autism Spectrum Disorder Multidisciplinary Clinics

A Partnership between:

Kentucky Commission for Children with Special Health
Care Needs

&

Kentucky Autism Initiative in Treatment Training and
Research



ASD Clinics

- First clinic was in the Fall of 2014
- Clinics have been held in five locations across the state, in Commission offices
- We are participating in a sixth location in Corbin at the CMHC with Dr. Barbosa
- All clinics have been very successful!



Overview

- Preparation
- Evidence Based Practices
- Clinic flow and Huddles
- Outcomes



Staff Training



- Partnered with Kentucky Autism Training Center (KATC)
 - Held 1-2 day trainings with clinic staff onsite
 - Informed participants about ASD
 - Discussed home and educational aspects of ASD
 - Advised how to modify clinic space for ASD clients
- Staff watched an additional 5 hours of evidenced based practice webinars regarding ASD
- **Although the patients were not new to the staff, they all felt the training was very helpful**



Clinic preparation

- All prior CCSHCN clinics have been medical clinics
- Now we added a behavioral health component
- We worked with Medicaid to add behavioral health codes into our profile

Multidisciplinary Clinic



- The advantage to the patient is that they can see several providers on the same day and leave knowing that everyone agrees on a unified plan
- The disadvantage is length of time spent in clinic for the family and child with ASD

Clinic Preparation



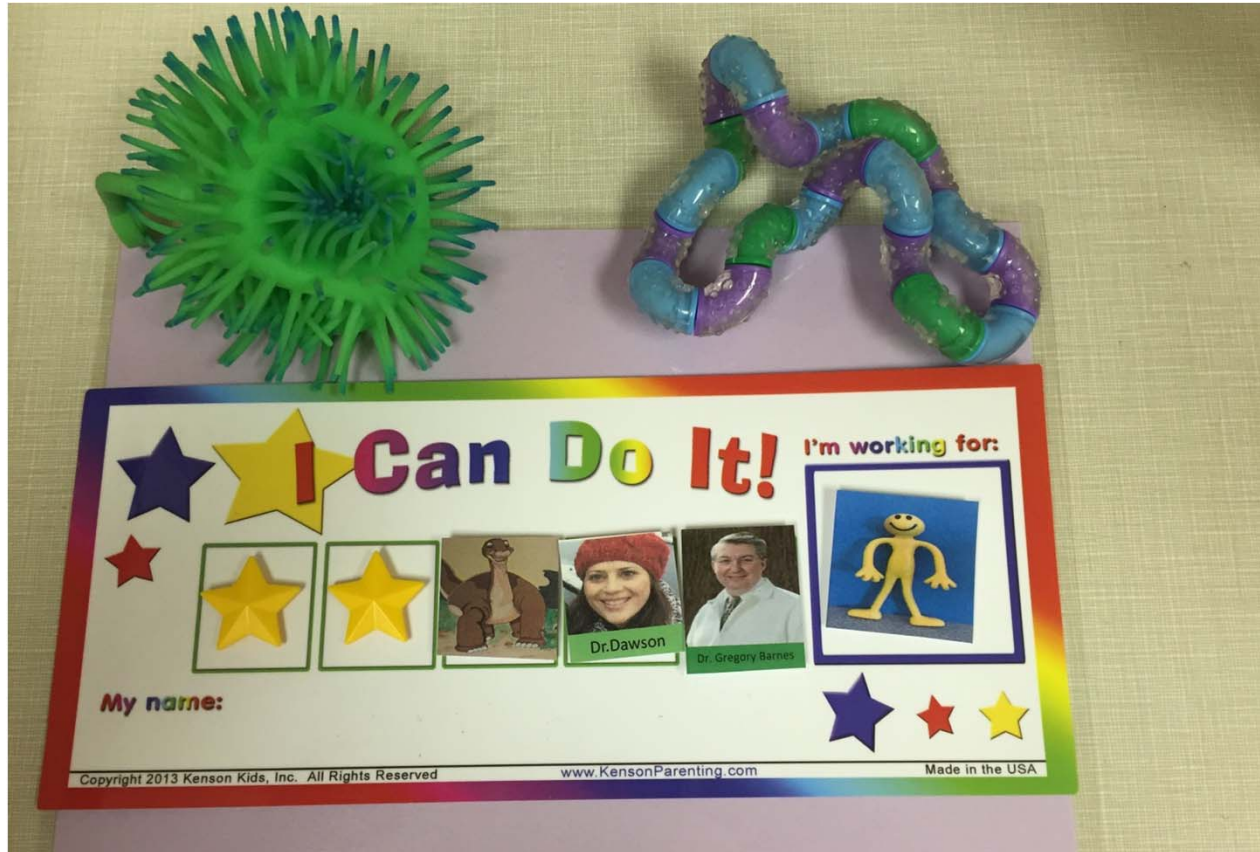
- Based on the web-based training and the face-to-face training with KARC, the staff made evidence based modifications to the clinics to prepare for ASD clinic:
 - Specific sensory items (special toys) were purchased
 - Visual schedules were created so the patients would know who they were scheduled to see that day
 - Triage was modified to allow the patients to choose what test was going to be done first
 - Light covers were purchased to help take away the harsh florescent lighting and make the exam rooms more sensory friendly

Visual Schedules



- Laminated card with boxes for each provider the patient will see that day and a picture of the reinforcer (prize)
- A small 1x1 picture of the provider will be attached to the board with Velcro
- After the patient sees the provider, the picture will be removed and replaced with a star to indicate completion with that provider
- Once the patient acquires all their stars indicates completion of all appointments, they have earned the reinforcer (prize)

Visual Schedule



ASD Clinic Providers

Treatment Clinic

- Developmental Pediatrician
- Child Neurologist as needed
- Child Psychiatrist
- Social Worker
- RN Care Coordinator
- Audiologist as needed

Diagnostic Clinics

- Developmental Pediatrician
- Child Psychologist
- Social Worker
- Speech Therapist
- RN Care Coordinator
- Audiologist as needed



New Providers

- Most providers were recruited from Louisville and Lexington
- With a long-term plan of sustainability collaboration with local providers is a must
- With the hope of building regional capacity we credentialed local Bowling Green providers to help staff that clinic and ECU providers to staff clinics in the East

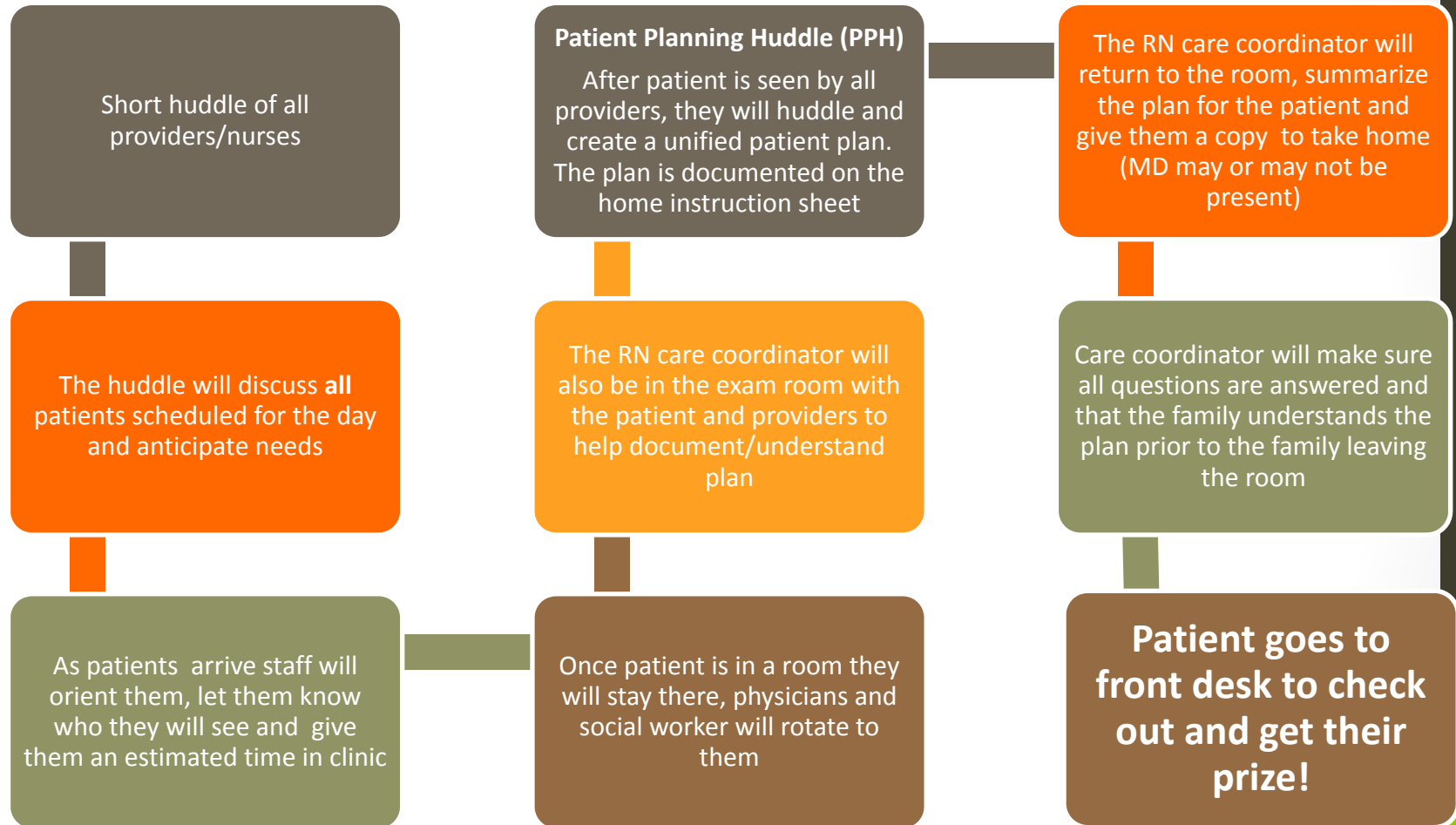


Clinic Preparation

- An ASD clinical history form was developed by the providers for the parents to complete prior to the visit, it included patient and family medical history, social and school history, prior studies, tests and results and psychiatric history/needs



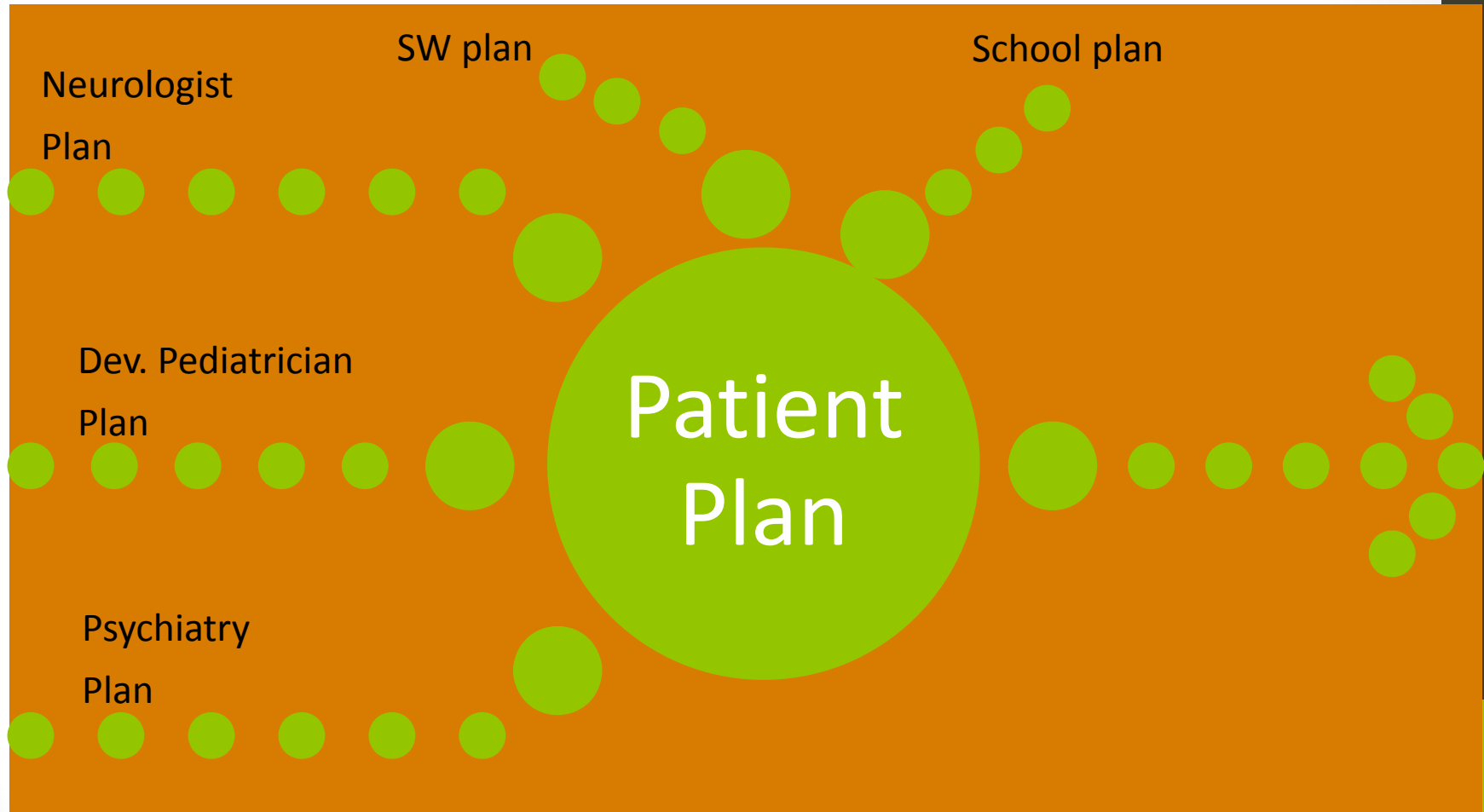
Provider Clinic Flow



Physician Work Flow

- Needed to develop tools for the physicians to use to help organize and streamline the Patient planning huddle and dictation
 - PWCS – Physician Working Communication Sheet – one template that each MD will write on summarizing what was discussed during the encounter, relevant issues the other MDs need to know and the preliminary plan for each MD – will be used in Huddle, dictation and filed in chart
 - Home Instruction sheet – a form to be used in Huddle that will also be used by nurse to summarize visit for family, families are included in the formation of the plan
 - Caregiver will get copy of this form when they leave

Many Providers - One Plan !



Advantages of the CCSHCN



- If questions crop up after the visit or the family needs help getting medications, labs or tests the RN care-coordinator will help answer questions, organize studies and help with school, IEPs and social services, families can even get help with transportation and gas money
- The families are not on their own once they leave the clinic, help is just a phone call away!

Outcomes



- 32 clinics as of January 31, 2016 (250 patients,
- (6 were telehealth)
- Western half of the state(Treatment)
 - Owensboro - 8 clinics, 60 patients
 - Paducah - 4 clinics, 29 patients
 - Bowling Green - 7 clinics, 57 patients
- Eastern half of the state (mostly diagnostic)
 - Lexington - 4 clinics, 17 patients
 - Somerset - 5 clinics, 20 patients
 - Corbin CMHC – 4 clinics 15-20 patients per clinic

Outcomes



- Average time in clinic was 3 hours
- More than 100 prescriptions written, multiple medications were adjusted
- Labs were ordered including chromosomal analysis
- Many referrals were made for various reasons to sleep specialist, nutrition, adolescent GYN etc.
- Families were helped with school issues and connected to services for wavier programs, given information on guardianship, connected to family groups such as Autism Speaks

Family evaluations



- All agreed or strongly agreed that they were satisfied with the care their child received
- All agreed or strongly agreed that they plan to attend a multidisciplinary clinic in the future
- All agreed or strongly agreed that they were leaving with a treatment plan developed and agreed upon by all providers
- All agreed or strongly agreed that they were satisfied with the clinic

Family evaluations - comments

- “Awesome as always”
- “I was very pleased with our visit”
- “Extra time was spent answering questions about _____’s future. _____ loved the picture schedule”
- “A clinic specific to Autism is a blessing and was very much needed, Thank you”





wait times



Pt.	Apt.	Arrived	Provider 1	Provider 2	Provider 3	Provider 4	Huddle	Exit	Total time
1	8:30	8:30	8:40-9:08 β	9:10-9:24*	9:48-10:32α		10:32	10:50	2hr 20min
2	8:30	8:30	8:50-9:30£	9:30-9:35*	9:35-9:55£	10:22-10:32β	10:35	10:54	2hr 25min
3	8:30	8:05	8:30-8:50*	8:50-9:14£	9:41-10:00β	11:05-11:30α	11:30	11:40	3hr 35min
4	10:00	10:15	10:30-10:47* 11:00-11:05*	10:47-11:00£	11:41-11:49β	12:40-1:07α	1:07	1:20	3hr 05min
5	10:45	10:45	11:05-11:30β	11:40-11:53*	11:53-12:22α	12:47-1:06£	1:07	1:15	2hr 30min
6	11:30	11:05	11:24-11:40*	11:50-12:21£	12:30-12:47β	1:30-2:10α	2:10	2:20	3hr 15min
7	1:00	12:45	1:20-1:35*	1:35-1:53β	2:00-2:25£	2:50-3:18α	3:18	4:00	3hr 15min
8	1:45	1:50	2:00-2:30*	2:35-3:05£	3:25-3:35β		3:40	4:00	2hr 10min
9	1:45	1:30	1:40-2:00*	2:20-2:35β				2:50	1hr 20min

(*indicates the social worker, α is Dr. W, β is Dr. B and £ is Dr. L)

Average time in clinic for patients who saw 3 physicians was 3 hours

Average time in clinic for patients who saw 2 physicians was 2 hours and 15 minutes

Diagnostic clinic times



Pt.	Apt.	Arrived	Provider 1	Provider 2	Huddle MD and Family	Exit	Total time	Dx
1	8:30	7:50	8:15-9:20 α	9:20-10:30 ∞	10:45-11:45	11:45	3hr 55min	no
2	9:30	8:20	9:20-10:40 α	11:10-12:12 ∞	12:30-1:40	1:40	4hr 10min	yes
3	12:30	12:30	12:45-2:00 ∞	2:18-3:30 α	3:30-4:00	4:00	3hr 30min	yes
4	12:30	1:15	2:00-3:10 ∞	4:00-4:42 α	4:42-5:00	5:00	3hr 45min	yes

(α is Dr. S and ∞ is Dr. M)

The 3 families that received the diagnosis of ASD were seen 2 weeks after diagnosis to make sure they understood the diagnosis and to answer all their questions.

Cost

- Many staff and providers are needed to conduct clinic
 - Physicians
 - Social workers
 - RN care coordinators
 - Therapists and Audiologists
- Reimbursement doesn't come close to the actual cost of the clinic
- At best 30% of provider cost is collected
- Provider cost is only a portion of overall cost
- Title V dollars are used to offset costs

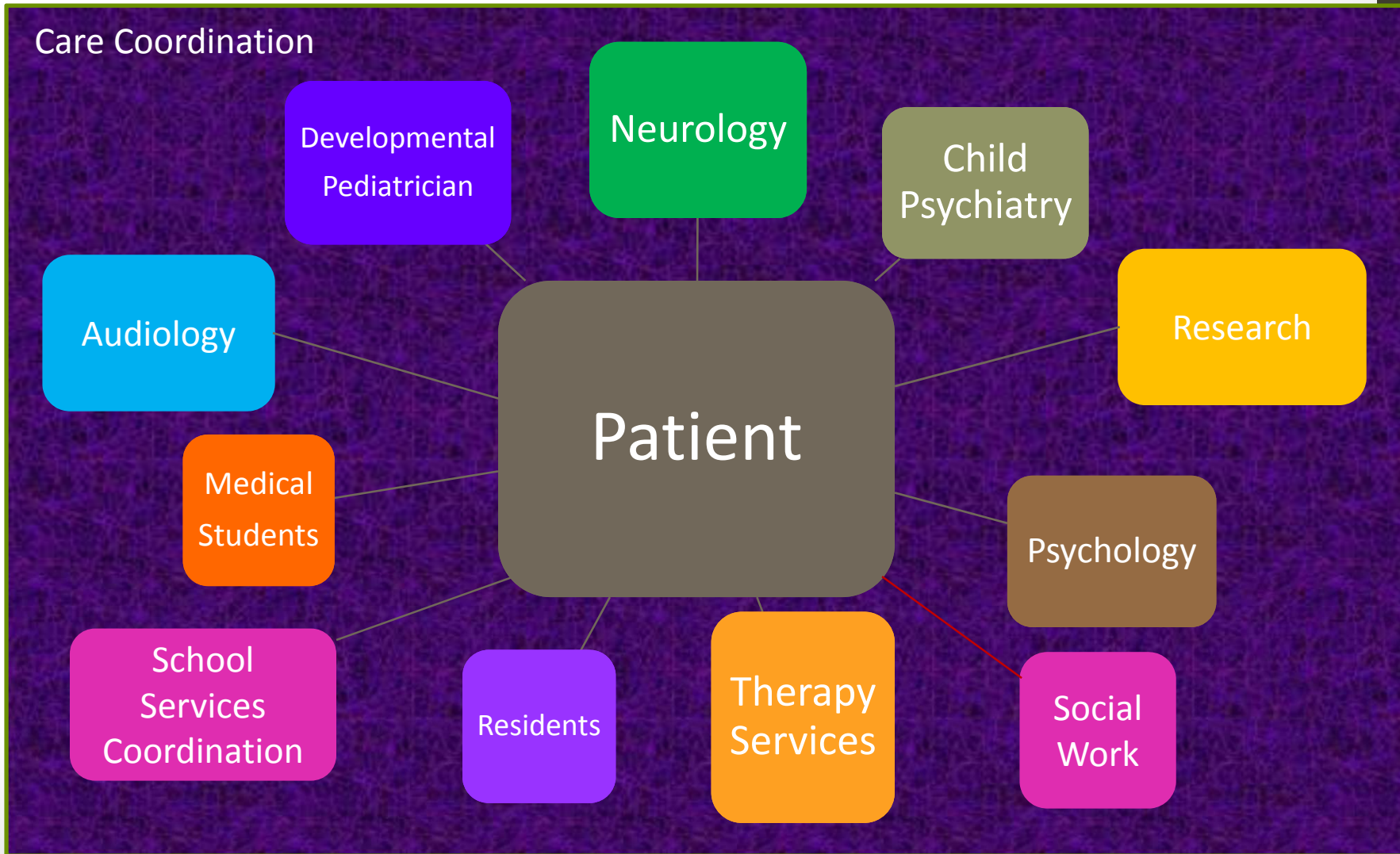


Summary

- Overall the clinics have been very successful
- We are looking at the clinic details and evaluations and trying hard to decrease wait time for patients
- Committed to continue clinics and increase the diagnostic evaluations in the east



The Future



Kentucky ASD Specific Services

